

Social Security Administration
Compassionate Allowance Outreach Hearing on Cancers
Monday, April 7, 2008

Denise Williams, LCSW
Social Work Department, St. Jude Children's Research Hospital

INTRODUCTION

Good afternoon, my name is Denise Williams. I am a Licensed Clinical Social Worker with St. Jude Children's Research Hospital in Memphis, Tennessee. I have worked with pediatric oncology patients and their families for over five years. Thank you for giving me the opportunity to participate in this hearing to discuss the impact childhood cancer has on patients and families and the need to find ways to provide them with social security benefits as quickly as possible.

The Mission of St. Jude Children's Research Hospital is to advance cures, and means of prevention, for pediatric catastrophic diseases through research and treatment. The main focus of these efforts has been the large set of life-threatening diseases known as cancer. Consistent with the vision of our founder Danny Thomas, no child is denied treatment based on race, religion, or a family's ability to pay. Approximately 400 children are accepted for cancer treatment each year. St. Jude Children's Research Hospital provides the patient with medical care at no cost to the family. The hospital does bill insurance if it is available but the family pays no co-pay or deductible. Additionally, the hospital offers assistance to supplement the cost of meals for the patient and one caregiver, as well as transportation and lodging at no cost to the family.

STATISTICAL DATA

During the past five years, St. Jude Children's Research Hospital has treated 2080 cancer patients. During this period, the five most common diagnoses treated at St. Jude are:

DIAGNOSIS	%
Acute Lymphoblastic Leukemia (the most common childhood cancer)	19
Acute Myelogenous Leukemia	7
Medulloblastoma (brain tumor)	6
Hodgkin's disease	6
Retinoblastoma (cancer of the eye)	6

Today, I would like to highlight the most common form of childhood cancer: Acute lymphoblastic leukemia (ALL). In the United States about 3,000 children each year are found to have acute lymphoblastic leukemia. Peak incidence occurs from 3 to 5 years of age. The five year survival rate for ALL is 94%. ALL affects lymphocytes, a type of white blood cells. Leukemic cells accumulate in the bone marrow, replace normal blood cells, and spread to other organs including liver, spleen, lymph nodes, central nervous system, kidneys, and gonads. In most cases, the child is treated with chemotherapy for 2 to 3 years. Hematopoietic stem cell transplantation is an option for very high-risk cases

(e.g., Philadelphia chromosome-positive ALL or slow responders to remission induction therapy), or those who develop an early relapse in the bone marrow.

IMPACT ON FAMILIES

When a child is diagnosed with cancer, the parents' immediate concern is to obtain the best care available for their child. This situation affects the family emotionally, physically, and financially. The parents may experience a broad range of feelings. Common reactions are denial, anger, guilt, grief, fear, and confusion. These reactions are natural. The patient and family may have to travel long distances to the treatment center; and in some cases placing them in an unfamiliar city or state. Due to the seriousness of the diagnosis, treatment often begins immediately. Parents are provided a great deal of information and nestled in a new vocabulary of medical terminology; which is all to be absorbed in a short period. With the added stress of medical appointments, diagnostic procedures, hospital admissions, and medication regimens, the parents can feel they have little to no control over their lives.

Let's take into consideration the patient who has been diagnosed with acute lymphoblastic leukemia (ALL), the most common form of childhood cancer and an illness that peaks in the three to five year old age group. I would like to help you further understand the enormous impact that this has on their lives and that of their family. When a parent is told that their child has a diagnosis of leukemia, they usually have very little time to prepare, arriving at St. Jude within hours of hearing that leukemia is suspected. Once the diagnosis is confirmed, treatment starts immediately. They begin very intensive chemotherapy called induction therapy which lasts for 6 weeks with the goal of achieving remission. The patient is required to stay in Memphis during this time when they are especially vulnerable to life threatening infections. The next phase is consolidation. This consists of four courses of high dose chemotherapy administered 14 days apart. If the child is not having complications, the child may return to the home community between these courses. After the consolidation phase, maintenance therapy begins and will continue for 120 weeks. There are two more periods of intensive therapy called reinductions that are given at week 7 through 9 and again at week 17 through 19. Although most maintenance therapy can be given weekly at a medical facility in the home community, there will be periodic return trips to St. Jude for chemotherapy in their spinal fluid. Also, during the entire two and a half years of treatment, these children must be monitored closely for infections, seek medical care immediately for fevers and can usually expect to be hospitalized for infections multiple times during the course of their treatment. Children determined to be standard risk or at high risk will receive more intensive treatment than children determined to be low risk. As you can see, Family Medical Leave is quickly exhausted during the initial phases of treatment and a child's access to third party coverage may impact where and how they get their maintenance therapy. As the social worker, I provide counseling to help the patient and family adjust emotionally to the crisis of the acute illness, as well as, help them prepare to manage the day to day responsibilities involved in caring for a chronically ill child during the lengthy treatment course. I also provide information about available resources including Supplemental Security Income in an effort to stabilize the family financially. Although ALL impacts children of all ages, the higher percentage of young children with ALL often means young families are impacted at a time in their lives when they are early in their careers and least likely to have a financial safety net. Therefore it is important for

the family to receive available financial resources as soon as possible. We have also found that eligibility for SSI can be the gateway for families to qualify for Medicaid as well as additional state specific resources. Moreover, obtaining these resources is critical for accessing ongoing medical care in their home community.

Those families whose expenditures have depended on two paychecks will face significant financial stress. Single parent families, as well as those with low wage employment, may experience even greater hardship. Moreover, patients treated at facilities where their insurance covers only part of the medical expenses or, in cases where the treatment facility is in a state where the patient's insurance is not accepted, the family often incurs monumental medical bills; further adding to their financial liability.

I would also like to briefly add that once the child is finished with treatment, the impact on the family does not stop there. In general, childhood cancer survivors often experience late effects both physically and psychologically. These complications, disabilities, or adverse outcomes are the result of the disease process, the treatment, or both and may affect the patient through-out his or her life span. When patients experience late effects that impact their physical and cognitive functioning, they may find that the impairments impede their ability to obtain suitable employment; thus lowering their lifetime earning potential. In addition, due to their health history, many survivors have difficulty obtaining adequate health insurance. Therefore, eligibility for SSI will help patients and their families continue to meet their financial needs.

St. Jude Children's Research Hospital has a long history, approximately 15 years, of working collaboratively with the staff at the Memphis Social Security office to assist families with the SSI application process. Our institution has a very large number of pediatric oncology patients admitted to our hospital annually. They come from all over the United States and remain in Memphis for an extended period of time while the child is undergoing treatment. Recognizing early on that the lengthy stay in Memphis impacted the family's ability to file locally in their home community, social work staff met with the local Social Security administrators to discuss ways to assist our patients in applying for SSI. The Memphis Social Security staff was extremely receptive to helping our patients and families in this process. In the early 1990's we scheduled a specific time and found office space for a representative from the Social Security Administration to come to St. Jude once a week to complete face to face eligibility interviews. The representative also assisted our patients with change in status reporting as well as filing appeals.

Due to the high volume of referrals and scheduling issues for parents and their clinic visits, we met again and decided to try phone interviews "on demand" wherein our patients and families could call in to the local office to complete the interview by phone. When this posed a challenge, we re-grouped and began a system of faxing leads to the Social Security staff. They would then contact the family by phone to begin the application process. The local office also provided SSA 827 releases forms and self-addressed envelopes to our Health Information Management Services (HIMS) staff to facilitate submitting the medical records to the Social Security office in a timely manner.

When electronic filing became available on-line, St. Jude Social Work staff and SSA administrative staff met and jointly developed a step by step basic instruction sheet for

families to help them navigate the on-line application process. This was a team effort not only between the Social Security Administration and Social Work staff but also other departments within St. Jude Hospital. The Linda Hajar Family Resource center at St. Jude has computers available to patients and parents 24 hours a day, 7 days a week. Two computers are dedicated to the families during the evening hours so that families can use them to apply for benefits. Our Information Technology Service department installed special software on these computers to provide them extended time if needed to complete the application. During the day, the Family Resource Center staff is available to help families with any computer problems or concerns. Our Health Information Management staff (HIMS) have been invaluable in working with us in this process and keeping SSA releases available to have parents sign to facilitate getting medical records sent to DDS to expedite this process. Additionally, our HIMS staff have worked one on one with Memphis Social Security staff-sometimes sending records to the local office that are then scanned into the system for DDS if there are problems with previously sent medical records. When we have families admitted to St. Jude that have filed for SSI prior to coming to St. Jude, and medical records are needed, our HIMS staff has sent records to the local Memphis office and they have scanned records in for other states to have to determine eligibility. Our new parent packet at St. Jude includes some of the information that we provided for you today that details the different ways to apply for SSI, as well as our step by step instructions for filing on-line. For those patients and families who lack computer skills, we continue to fax over leads to the Memphis SSA office for phone interviews.

There are several important key elements that have facilitated the success we have had with this process over the years. First and foremost have been the joint meetings between St. Jude staff and the Memphis SSA administrative staff. When we have encountered problems within our system, we have come to the table to evaluate the process and make changes to address the problems. Additionally, on individual cases with problems, there is close collaboration with local SSA representatives, the patient's social worker, and the family to solve specific problems. Because St. Jude treats a culturally diverse population, when we have needed an interpreter, our Interpreter Services staff has worked closely with SSA staff on the phone.

We hope that the information that we have shared about our experiences with the SSI process for pediatric cancer patients at St. Jude is helpful to you as you proceed with developing the standards for Compassionate Allowances.

Thank you on behalf of our patients and their families as well as St. Jude Children's Research Hospital for the opportunity to testify today.